

Counseling Students who Have

Usher Syndrome

Introduction

Usher Syndrome is an autosomal recessive genetic disorder characterized by congenital hearing loss and gradually developing retinitis pigmentosa leading to the loss of vision. Approximately 27,000 people in the United States have some form of Usher Syndrome. Most of these individuals have either Type I (11,000) or Type II (16,000).

Type I Usher Syndrome is characterized by profound congenital deafness, vision problems starting in early childhood, and severe balance problems.

An individual born with a moderate to severe hearing loss and normal balance characterizes Type II Usher Syndrome. Night blindness for Type II begins at childhood, but many individuals might not be aware of it until late adolescence/early adulthood.

Historically speaking, around 10 years ago, most students with Usher Syndrome Type I attended residential schools and colleges for the deaf, while individuals with Type II attended regular public schools and universities. With the mainstreaming of deaf and hard-of-hearing students brought about by Public Law 94-142, students with both Type I and II Usher Syndrome can be found in all types of educational settings.

It is critical for support service personnel and counselors in college/university environments who work with students with Usher Syndrome—regardless of type—to have a good understanding of special issues that arise for these students and to be aware of strategies that will benefit this population.

It also is critical that professionals have a good

understanding of Usher Syndrome and what it means to be deaf/hard of hearing and to be losing one's vision. College-age students with Usher Syndrome have many of the same developmental issues as other adolescents (age 18 to 24 years). However, students in this population have additional issues that are not encountered by students who have normal hearing and vision or even their deaf and hard-of-hearing peers who have normal vision. The purpose of this tipsheet is to identify particular issues of concern for those who counsel college-age students who have Usher Syndrome and list some strategies, tips, and resources for both professionals and students.

Counseling students with Usher Syndrome and their psychological issues:

The first rule of thumb is never to assume what the student does or does not know about Usher Syndrome. Assess his or her knowledge about the medical aspects as well as what he or she knows about services available to people who have Usher Syndrome.

Many students find it difficult to be open about their personal-social needs, so this is a good place to start. As a support service professional or counselor, your first priority should be to do a needs assessment interview with the student. Find out what he/she needs from you. Develop a list of questions related to psychological issues such as:

Personal/Social and Life Issues

- How will the student feel about his/her interactions with peers when communication in groups and/or in dark places is difficult, due to diminishing dark adaptation and shrinking visual field?

- How will the student adapt to changes in vision and hearing? What about his/her independence? What about driving a car?
- What special concerns will the student have related to dating and relationships? Does he/she feel isolated, misunderstood and/or not accepted by peers?
- What is the impact of Usher Syndrome on relationships and/or marriage?
- Has the student shared his/her thoughts and feelings about Usher Syndrome or visual challenges with family or loved ones? Is it difficult or easy to share?
- Will the student be able to raise children properly? If yes, what are his/her fears and hopes about whether they can do it or not?
- What are some of the positive and negative experiences of people who have Usher Syndrome?
- Where can role models be found?
- What organizations, services, and professionals can help the student move from being a deaf/hard-of-hearing person with vision limitations to becoming legally blind?
- How can the student deal with issues related to anger, guilt, shame, depression, and fear of dependency?
- What if the student does not want to discuss or even acknowledge his/her Usher Syndrome?
- Does the student have any concerns about his/her chosen career and future?

Strategies for Career Development Issues

Do research and educate yourself about careers of people who are deaf/blind to assist students with concerns or confusion about career choice. It is hard to predict how each person's vision might change with age.

Some will become totally blind by the age of 40 and others might keep a good part of their central vision until they are in their 70s.

It is not the counselor's role to tell students what career to choose. The counselor should help the student understand that many people change career paths three or four times in their lifetime. Encourage the student to research career options. Also encourage the student to learn as much as possible about Usher Syndrome and how it might influence the future and career choices, especially where to go to receive professional or vocational training..

Some of the jobs held by people with Usher Syndrome:

Researcher, professor/author, chef/owner of restaurant, lawyer, certified public accountant, information technology specialist, computer programmer, public health manager, counselor/professor, minister, librarian, veterinarian, health planner, clerk, medical transcriptionist, mental health counselor, high school teacher

Share this information with students so that they realize that people with Usher Syndrome do have successful careers.

Strategies for Personal/Social/Life Issues

- Often a student will not be emotionally ready to deal with having Usher Syndrome. If the student is functioning well academically and personally, leave the denial alone. Denial is an important aspect of how people protect themselves mentally until they are ready emotionally to deal with having Usher Syndrome. Of course this often makes it hard to work with students who are not functioning well academically or emotionally because of their Usher Syndrome. In this case, it is important to gently try to help the student understand how his/her changing vision or lack of vision is having a serious impact on how he/she functions in the classroom or with peers. If a student does

not want to talk about these issues, it is best to leave him/her alone.

- Sometimes acceptance is not possible if the visual problems are not yet apparent.
- If the student is having problems communicating in group settings or dark places, encourage the student to be more open about having Usher Syndrome and talking about his or her communication needs with close friends.
- Encourage the student to meet other people who have Usher Syndrome (role models), especially adults who have learned how to adapt and make modifications in their lives to function well and independently. This can be done through the Internet and also by contacting organizations that involve people with Usher Syndrome. (See resources list.)
- Find out about organizations, e.g. Helen Keller National Center, and websites that will help you as a professional but also help your student. (See resources list.)
- If possible, try to find a person who has Usher Syndrome who can function as a role model and mentor for your student. We all know how important it is for deaf and hard-of-hearing students to have role models and peer groups. The same is true for students who have Usher Syndrome.
- If a student is depressed, angry, and afraid, suggest counseling services. If you feel you are not qualified to work with clients on those issues, seek out a qualified therapist to whom you can refer the student or if there is a support group for visually challenged students at a local college where the student attends, encourage him/her to attend a meeting.
- Consider encouraging the student to attend a special summer program at Helen Keller National Center for adolescents and young adults. This program give sstudents an opportunity to be with peers who have

Usher Syndrome and meet older adults who have Usher Syndrome. It also offers an overview of career possibilities, orientation and mobility, independent living skills, and computer and communication adaptive technology, and will help them to be more independent and assertive about their needs.

- Do not assume that all problems the student might have are the result of having Usher Syndrome. Ask questions and listen carefully to the student's thoughts and feelings regarding his/her identity as a visually challenged student, then provide support and information on resources.
- Offer hope and be honest. If the student asks, "Will I go blind?" the answer is, "I do not know." No one knows what will happen for any particular person.
- Be open, accessible, and approachable to the student. Be educated on Deaf/Blind and Usher Syndrome issues including medical, advocacy, and psychological issues.

Resources

DBTeens is a private email Internet forum for teens and young adults to share information, ideas, opinions, and other issues for people who have Usher Syndrome or are deaf/blind. To subscribe, contact owner Ralph Klumph at klumphr@wou.edu. Send the message "subscribe DBTeen."

Usher Syndrome List

An Internet forum for people with Usher, their parents, friends, spouses, and service providers. To join this list via Yahoo! Groups, go to <http://groups.yahoo.com/group/Ushers/join>. To subscribe, click on Join.

Organizations that provide information or services

American Association of the Deaf/Blind
814 Thayer Avenue
Silver Spring, MD 20910
301-588-6545 (T)

301-588-5705 (V)
aadb@erols.com

Center for the Study and Treatment of Usher Syndrome
Boys Town National Research Registry for Hereditary Hearing Disorders
(National Institute on Deafness and Other Communication Disorders)
555 North 30th Street
Omaha, NE 68131-9909
800-835-1468 (V/T)
402-498-6331 (F)
genetics@boystown.org

NTID Vision Support Committee
National Technical Institute of the Deaf
Rochester Institute of Technology
52 Lomb Memorial Drive
Rochester, NY 14623
Bryan Lloyd, Chair
(866) 927-1297 (Video phone)
bslnsl@rit.edu

DB-LINK
The National Information Clearinghouse on Children Who Are Deaf-Blind
Teaching Research Division
Western Oregon University
345 N. Monmouth Avenue
Monmouth, OR 97361
800-438-9376 (V)
800-854-7013 (T)
503-838-8150 (F)
www.tr.wou.edu/dblink
dblink@tr.wou.edu

The Foundation Fighting Blindness
Executive Plaza I, Suite 800
11350 McCormick Road
Hunt Valley, MD 21031-1014
888-394-3937 (V)
410-785-1414 (V)
800-683-5551 (T)
410-785-9687 (T)
410-771-9470 (F)
www.blindness.org

Helen Keller National Center for Deaf-Blind Youths and Adults (HKNC)
111 Middle Neck Road
Sands Point, NY 11050-1299
516-944-8900 (V)
516-944-8637 (T)
516-944-7302 (F)
www.helenkeller.org
hknctrng@aol.com

These are web site links that will connect you to other resources and various web sites that have information about Usher Syndrome as well as deafness/blindness in general.
www.tr.wou.edu/dblink/links.htm
www.tr.wou.edu/dblink/source.htm

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